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## PROJECT REPORT

# The Cumbria Rural Health Forum: initiating change and moving forward with technology

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## ABSTRACT

**Introduction:** The Cumbria Rural Health Forum was formed by a number of public, private and voluntary sector organisations to collaboratively work on rural health and social care in the county of Cumbria, England. The aim of the forum is to improve health and social care delivery for rural communities, and share practical ideas and evidence-based best practice that can be implemented in Cumbria. The forum currently consists of approximately 50 organisations interested in and responsible for delivery of health and social care in Cumbria. An exploration of digital technologies for health and care was recognised as an initial priority. This article describes a hands-on approach undertaken within the forum, including its current progress and development.

**Methods:** The forum used a modified Delphi technique to facilitate its work on discussing ideas and reaching consensus to formulate the Cumbria Strategy for Digital Technologies in Health and Social Care. The group communication process took place over meetings and workshops held at various locations in the county.

**Results:** A roadmap for the implementation of digital technologies into health and social care was developed. The roadmap recommends the following: (i) to improve the health outcomes for targeted groups, within a unit, department or care pathway; (ii) to explain, clarify, share good (and bad) practice, assess impact and value through information sharing through conferences and events, influencing and advocacy for Cumbria; and (iii) to develop a digital-health-ready workforce where health and social care professionals can be supported to use digital technologies, and enhance recruitment and retention of staff.

**Conclusions:** The forum experienced issues consistent with those in other Delphi studies, such as the repetition of ideas. Attendance was variable due to the unavailability of key people at times. Although the forum facilitated collective effort to address rural health issues, its power is limited to influencing and supporting implementation of change. Within the implementation phase,



the forum has engaged in advising and facilitating policy change at all levels. Thus, the forum has become a voice to influence change towards the advancement of health and social care through digital technologies. The forum continues to serve as a think tank and influencer for change in rural health and social care issues in Cumbria. The forum has increased awareness of digital health and social care solutions, mapped best practice and developed a digital strategy for health and social care in Cumbria.

**Key words:** digital technology, e-health, England, health services, needs and demand, social care, strategy, telecare, telehealth, telemedicine.

## Introduction

### *Background*

Cumbria is the second largest county in England by area. Its population, at 495 000, makes it one of the most sparsely populated. Half of Cumbria's total population live in areas that would formally be defined as rural<sup>1</sup>, and the urban centres are relatively small and geographically dispersed<sup>2</sup>. This rurality is not unique to Cumbria and is known to cause specific problems in the delivery of health and social care<sup>3-5</sup>.

Accessibility to key local services in Cumbria (including GP appointments and hospitals) currently exceeds national average times in the UK<sup>2</sup>. Delays in hospital admissions due to administrative procedures have previously been documented<sup>3</sup>. The high rate of suicide amongst farmers in remote areas in Cumbria initiated efforts to encourage people to seek help for their mental and physical health and minimise the relative inaccessibility of primary care, particularly in remote areas<sup>4</sup>. For example, an outreach model was designed to deliver general health care to farmers by using nurse practitioners<sup>5</sup>. Another problem has been the risk of hospital closures due to a recruitment crisis faced by local authorities in Cumbria<sup>6,7</sup>.

The Cumbria Rural Health Forum was formed in September 2013 to address the following questions related to the delivery of health and social care in Cumbria:

1. What does good rural health and social care look like?
2. How can digital technology address some of the issues?

Initial forum meetings built a consensus for a program of work to develop a strategy for future implementations of digital health and social care technologies based on issues relevant to Cumbria. In April 2014, the Cumbria Rural Health Forum received funding from the Academic Health Science Network for the North East and North Cumbria to enable a research team from the University of Cumbria to be engaged. This article aims to provide a concise description of the Cumbria Rural Health Forum, detailing its work, current progress and future intentions.

### *Aims and priorities*

The forum aims to improve health and social care delivery for rural communities, and share practical ideas and evidence-based best practice that can be implemented in Cumbria.

The priorities of the forum during 2014–2016 are:

- to explore the value of digital technologies in health and social care, including telehealth, telemedicine, telecare and assistive technologies, and e-health
- to influence and provide evidence to implement changes in health and social care
- advocacy and representation.

### *Membership*

The forum comprises a varied membership involving health and social care providers from the public, private and third sectors, digital technology companies, health and care social commissioners and policy makers in Cumbria. Membership started at 30 in 2013 and has increased to 158 members from



56 organisations from private, public and third sector agencies. Membership is open to any organisation or representative body that is interested in contributing to the forum's mission – either based in Cumbria, providing health and/or social care services to Cumbria, or planning to do so.

## Methods

### *The Delphi method*

The forum adapted the Delphi method<sup>8,9</sup> for conducting its work through meetings and workshops between stakeholders to reach agreement toward agreed actions, tasks and issues in discussion (Fig1). The Delphi method was originally developed as an interactive consensus-orientated technique relying on a group of experts answering collected data from respondents in rounds<sup>10,11</sup>. It has been used in various fields of study such as project management<sup>12</sup>, geriatrics<sup>13</sup>, operational research<sup>14</sup>, social policy<sup>15,16</sup> and information systems<sup>17,18</sup>.

While the Delphi method is normally survey-based, the method was adapted in the present study to be used in group settings<sup>11</sup>, combined with the open innovation approach<sup>19,20</sup>. Open innovation is 'the use of purposive inflows and outflows of knowledge to accelerate internal innovation, and to expand the markets for external use of innovation'<sup>21</sup>. It encourages the use of internal and external ideas, reflected in the sharing of best practice relevant to Cumbria, and making connections with both internal and external resources<sup>22</sup>. The following modifications were made to the Delphi technique used by the forum:

- group discussions through forum meetings, including feedback on email and discussions on social media
- discussion and generation of structured statements at roadmapping workshops
- incorporating elements of open innovation where the sharing of best practice with forum members was held to set the context for them to fully understand the purpose and aims of the forum. Forum members were also invited to answer

questions and to work together on specific exercises relevant to the issues in discussion.

In the whole-group modified Delphi method used by the forum, members worked in groups, either answering questions or carrying out implementation exercises, and reported back to the full meeting, using flip charts and verbal feedback. A brief session of questions then followed for clarification. In addition to the group work, there was sharing of best practice through presentations on digital health and social care issues, services or projects, either locally or outside Cumbria. Information about what went on during forum meetings and workshops was emailed to all members. This updated people who were unable to attend meetings and enabled them to send any comments, thoughts or feedback by email. The forum used Twitter to conduct four chats on digital health technologies. All information was collected and sorted into lists to be fed back to the Delphi rounds.

### *Issues relevant to Cumbria*

The first stage of the process was to confirm a common understanding of the rurality issues that were considered to affect delivery of health and social care services to the Cumbrian population:

- dispersed communities, meaning that people have limited access to services and have to travel further to access basic health care
- smaller GP practices and other health centres, meaning that staff may feel professionally isolated and removed from opportunities for professional development
- a greater reliance on volunteer services
- a population that comprises relatively more older people than in urban centres
- poor quality broadband and mobile infrastructure in Cumbria.

The first forum workshop also confirmed that the use of digital technologies in improving health and social care in Cumbria was a key priority for the forum (see Appendix I for the outline of forum events).

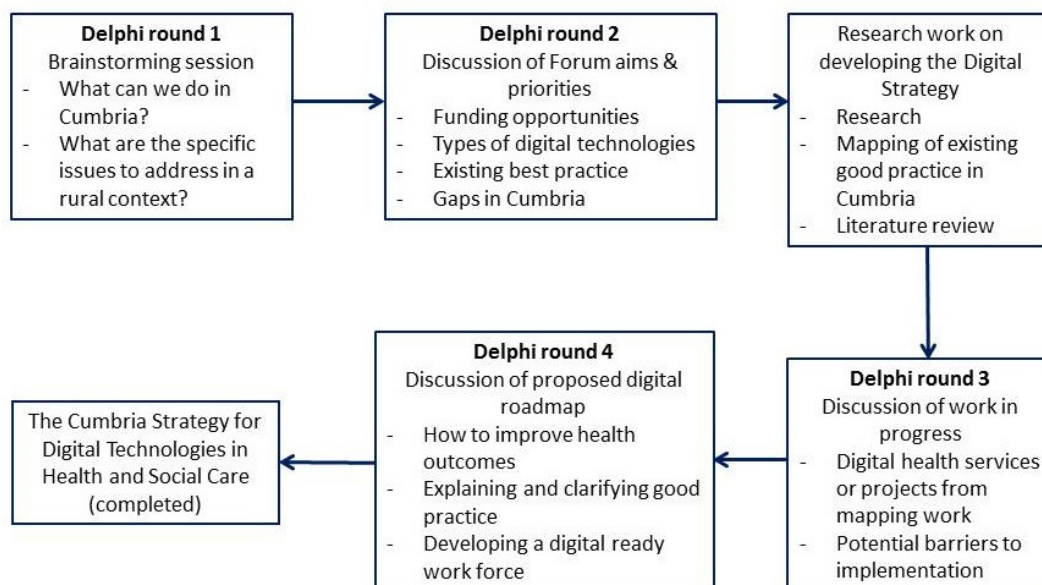


Figure 1: Adapted Delphi technique used by the Cumbria Rural Health Forum.

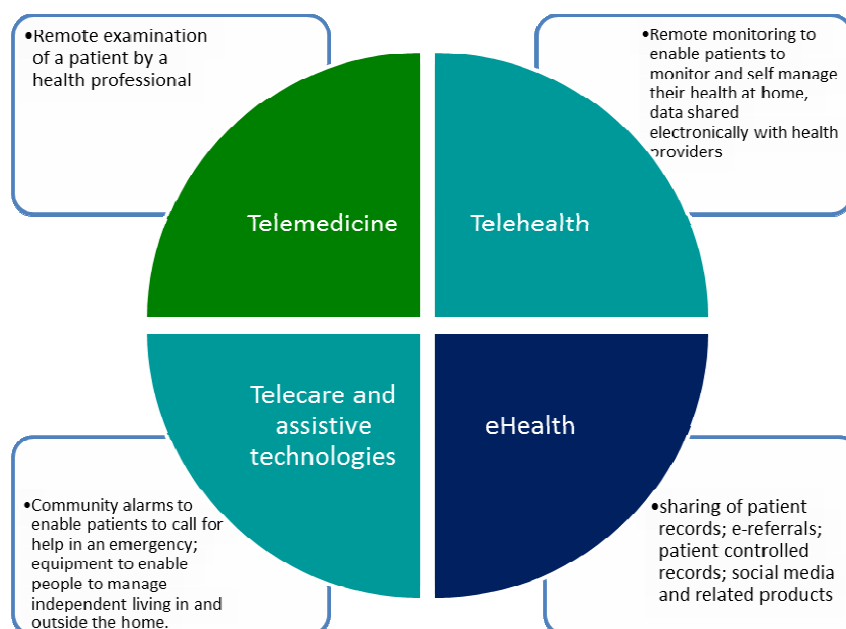


Figure 2: Agreed scope and terminology used by Cumbria Rural Health Forum.



It was agreed at the outset that the strategy work should not be limited to any particular technology. Digital health terminologies have been used differently in the literature by different authors<sup>23-25</sup>. To clarify the subtle differences in these terminologies and avoid confusion, the forum adopted agreed definitions of terms (Fig2). It was agreed to exclude technologies in development (eg new types of wearable sensors) and the use of digital technology for purely administrative purposes (such as online appointment booking).

The program of work was planned around the following objectives:

1. Map existing digital health and social care practice within Cumbria and transferable best practice from elsewhere.
2. Gain understanding of issues specific to rural health and social care.
3. Identify needs and opportunities for use of digital technologies (eg for remote consultations).
4. Develop a roadmap for implementation within Cumbria, including roles of key organisations, implementation plans.

## Ethics approval

Part of the original work described in this article were two qualitative original research studies, which were granted ethics approval by the University of Cumbria Research Ethics Committee (ref. 14/08, involving general practitioners and practice managers; ref. 14/10, involving people with long-term health conditions). These studies were carried out to investigate the role of digital technologies from the perspectives of healthcare professionals (GPs) and patients (appendixes II and III).

## Results

The findings are available on the forum website<sup>26</sup>.

## *Working on the Cumbria Strategy for Digital Technologies in Health and Social Care*

The program was undertaken over a 15-month period, shown on the timeline in Figure 3. The forum's work is presented in Appendix I. An investigative program underpinned the digital roadmapping workshops to gather necessary data to inform the forum and provide a basis for discussion<sup>27,28</sup>.

- To map existing digital health practice in Cumbria, forum members shared information on projects or services currently available in the county, including those that had expired. A total of 27 digital health and social care activities were reported. A full report is available online<sup>29</sup>. Informal interviews with members of staff working on the digital health projects or services allowed the research team to understand work conditions, staff experience and how the services were provided.
- A literature review on digital health and its application in international rural areas was carried out. The literature review found similarities to Cumbria in problems accessing health care experienced by people living in remote areas<sup>30,31</sup>, workforce issues<sup>32-34</sup> and use of digital health technologies<sup>35-38</sup>, which are either being planned or have recently been implemented<sup>39-41</sup>. Other issues were socioeconomic status of rural communities<sup>42-44</sup>, mental health problems<sup>45-49</sup> and the implications of digital technologies for managing long term conditions<sup>40,50-52</sup>. A report on the literature review is available online<sup>53</sup>.
- Two qualitative studies involving practice managers ( $n=5$ ), general practitioners ( $n=15$ ) and people with long term health conditions ( $n=25$ ) were examined. Further information on the studies is available online<sup>26</sup>. The studies indicated that:
  - telephone triage was increasingly being adopted by general practices as a means for patients to access healthcare. When asked about using digital technologies for





- consultations, practice managers recognised the potential benefits of remote consultations
- general practitioners believed that digital technologies could help reduce demand for their involvement in minor illnesses through improving transactional efficiency in the provision of services. Digital technologies in social media could be used to educate and empower patients
- people with long term health conditions expressed willingness to use remote consultations if it was made available to them, and welcomed the prospect of email or secure messaging with their care providers. Researchers found a lack of knowledge of possibilities, such as access to electronic health records.

All findings were synthesised and fed back into the forum through the roadmapping workshops for members' views. Consensus was reached by the forum on the following:

- The international literature review reflected similarity of experience relevant to Cumbria.
- The mapping work found that efforts to adopt digital technologies have already begun in Cumbria, but there were highlighted areas for improvement.
- Both professionals and patients recognised the potential benefits of integrating digital technology into health and social care in Cumbria.
- It was recognised that staff need training and skills development specific to digital care services and technology for successful implementation.
- All digital technologies reviewed were thought to offer some benefit to rural communities, particularly where they can be used to avoid travel by either a patient or care professional.

## *Finalising the strategy*

Three major themes were finalised for the roadmap on implementing the Cumbria strategy for digital technologies in health and social care (Fig4):

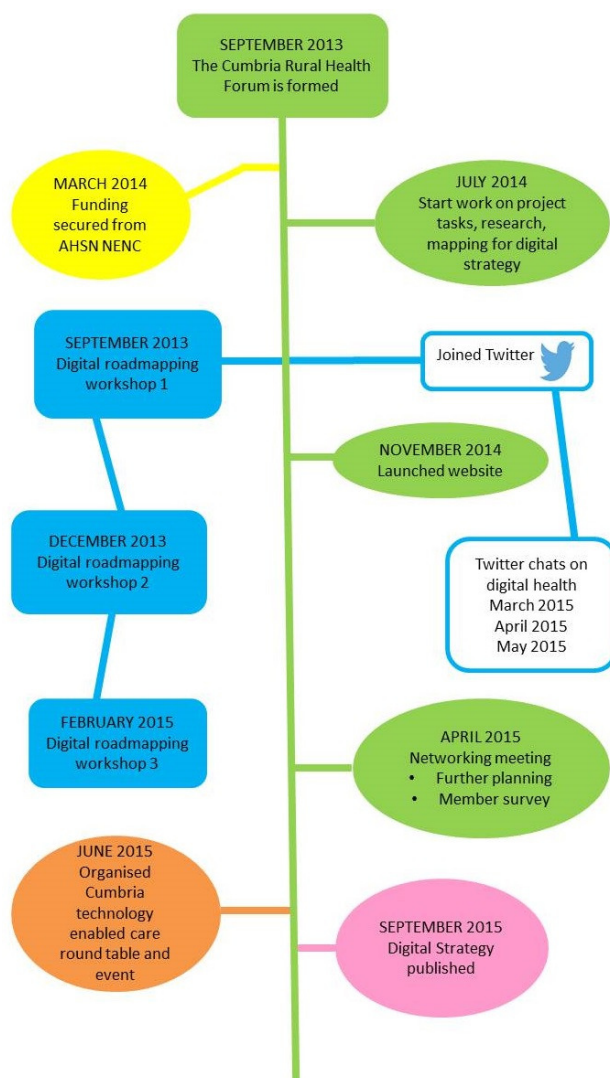
**Improve health outcomes through use of digital technology:** Successful planning needs to focus around particular problems or care pathways. The implementation plan will proceed through thematic workshops linking small groups of professionals working on a single pathway, patient group or service.

**Explain, clarify, share good (and bad) practice, assess impact and value:** The evidence base now assembled supports a growing role in influencing and advocacy. The dissemination, communication, information sharing and collation, networking and discussion activities will continue.

**Develop a digital-health-ready workforce:** The forum will work on defining a set of minimal required skills for digital health and social care, to enable design and delivery of services in clinical settings<sup>54</sup>. The use of e-learning and video-conferencing for training and development will be considered<sup>55,56</sup>.

## *Lessons learned and implications*

Findings from the forum have significant implications for practice, where multi-organisational consensus building is planned. The forum experienced issues consistent with those of other Delphi studies<sup>57</sup>. The number and representativeness of people at Delphi rounds affect the potential for ideas and how evaluation and consensus is reached<sup>58</sup>. There were some irregularities in meeting or workshop attendance. Despite holding a membership of more than 100 individuals, attendance at meetings was in the range of 20–30 people. The exact representation of stakeholder organisations also varied. To ensure full participation and involvement of all stakeholders, open-ended feedback by email was accepted from stakeholders who could not attend forum events. Stakeholders were encouraged to provide additional comments or express disagreement.

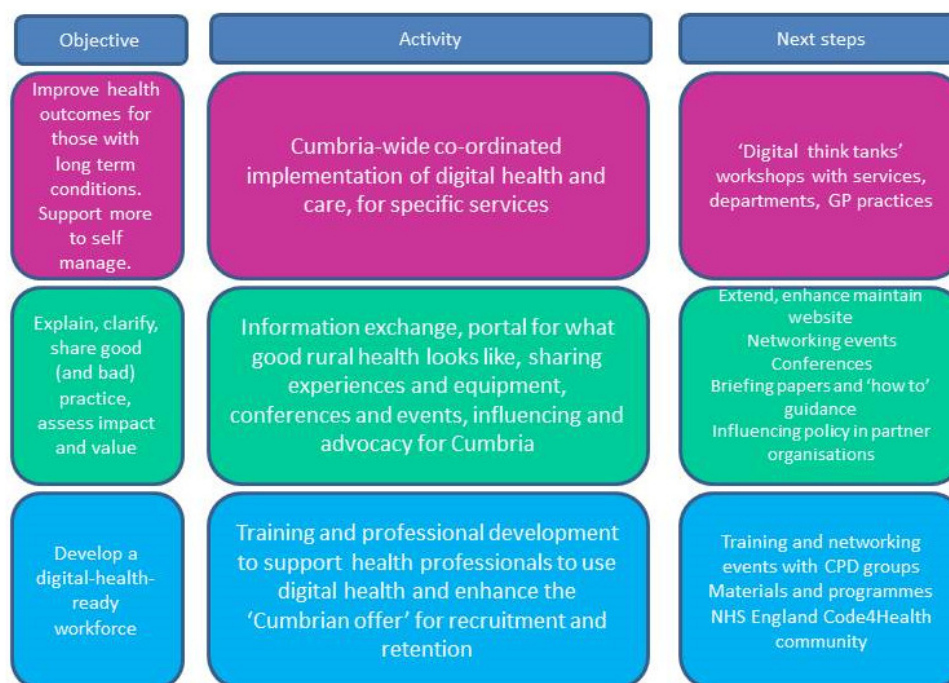


**Figure 3: Cumbria Rural Health Forum timeline.**

The next issue was not being able to engage key people during discussions – particularly GPs, who were frequently unable to attend due to clinical commitments. To ensure that their views could be received, Twitter was used to hold live discussions on digital health topics. To date, four Twitter chats have been held (available at <https://storify.com/CumbriaRHF/crhfchat>). The forum's Twitter chats generated keen interest in future collaborative efforts, particularly at primary care level (Appendix IV).

The forum experienced issues common to group problem solving<sup>59</sup>, such as 'group rut' where a group seems to have the same discussion repeatedly, regardless of the current agenda. To remedy this group rut, forum participants were reminded of the goals of the group work or exercise in question. Structured exercises were used during workshops<sup>60</sup>. Poor follow-through<sup>61</sup> was also experienced amongst a few stakeholders, where they had not fully understood the purpose of a particular meeting or workshop.





Note: The NHS England Code4Health community adopts an open-to-all approach in creating a collaborative workspace for people involved in finding digital solutions to improve healthcare in the National Health Service (NHS).

CPD, continuing professional development.

**Figure 4: Roadmap for Cumbria Strategy for Digital Technologies in Health and Social Care.**

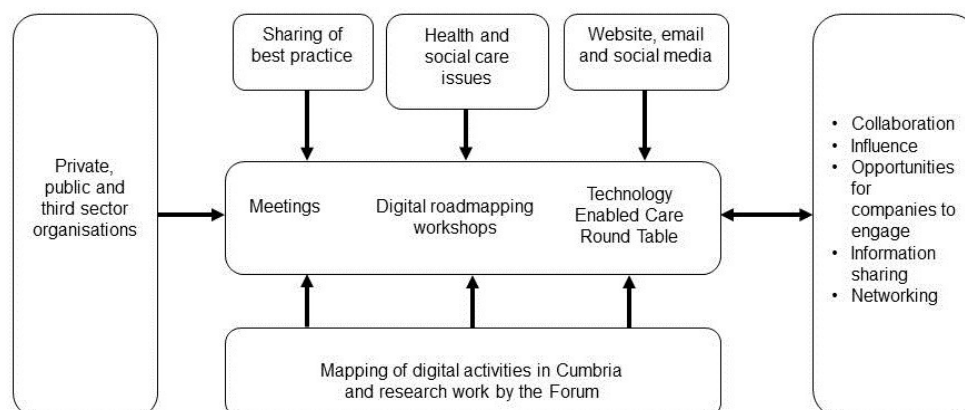
To gain understanding and foster familiarity in working together as a forum, participants were reminded of previous discussions and updated on investigative work. This helped to encourage interest, ownership and active participation amongst stakeholders<sup>62</sup>.

The forum facilitated collective effort to address rural health issues, but it does not have any mandate to deliver change directly. It is emerging as an important think tank and influencing body.

Forum events provided opportunities for the sharing of best practice, discussion of health and social care issues and networking (Fig5). More significantly, the forum has influenced emerging policy within the Cumbria health economy and discussions are in progress to formulate an ongoing advisory role to senior policy and decision makers.

## Conclusions

The forum has been successful in galvanising the interest and support of more than 50 organisations and more than 150 professional individuals in Cumbria, concerned with exploring important questions of mutual interest. The involvement of the voluntary or third sector and the private sector and dialogue with public sector bodies has been a particular achievement. The modified Delphi process adopted has presented some difficulties and limitations, but has ultimately led to a shared implementation plan, which has been successful in securing additional funding support. Awareness has been increased of digital health and social care solutions and a body of evidence has been compiled. The forum is recognised as an important think tank and influencing body, with a wider dissemination and advocacy role.



**Figure 5: Overview of Cumbria Rural Health Forum roles, activities and interactions.**

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## Appendix I: Outline of Cumbria Rural Health Forum events

Date	Location	Events/discussions/group work	Rural health topics discussed
17 Sept 2013	University of Cumbria campus at Energus, Workington (28 attendees)	What are the specific issues to address in a rural context? Can digital technologies help? Who needs to be involved/influenced? What can we do now and what do we 'park' for later?  Exchange of ideas and best practice from elsewhere  Brainstorming session on what we could usefully do in Cumbria	–
17 Dec 2013	Cumbria Rural Enterprise Agency, Penrith (26 attendees)	Discussion of other funding opportunities  Group to identify: a) Types of remote monitoring b) Known projects in Cumbria c) Known good practice elsewhere d) Gaps in Cumbria we would like to develop  Prioritisation of opportunities and agreed actions	Funding call from the Academic Health Science Network – North East North Cumbria by Seamus O'Neil, ENC AHSN
25 Feb 2014	Eden Housing, Penrith (29 attendees)	Update on the story so far and where we are now Outline of plans and bids submitted Communications and project portal	Cumbria Strategy for Digital Technologies in Health and Social Care – paper on telehealth and telecare by John Roebuck, Cumbria Clinical Commissioning Group
15 April 2014	University of Cumbria, Ambleside campus (25 attendees)	Update on business issues Project plan for the Cumbria Strategy for Digital Technologies in Health and Social Care  Mind map for web portal Networking	Patient transport needs by Lorraine Smyth, Action with Communities in Cumbria  How healthcare information resources can support rural professional development by Sarika Shah, Merck, Sharp & Dohme, Inc. (UK subsidiary)
10 June 2014	University of Cumbria Fusehill Street campus, Carlisle (27 attendees)	Update on business issues and projects	Measurement and evaluation to improve care and patient outcomes in the north east by Dr Jackie Gray, Medical Epidemiologist, North East, Quality Observatory System  Report on the stakeholder event of the Academic Health Science Network North East – North Cumbria held in May by Lisa Sewell, Chief Clinical Information Officer Project Manager, Northumbria Healthcare National Health Service Trust
16 Sept 2014	Carlisle Business Interaction Centre (32 attendees)	<b>Digital Strategy Roadmapping Workshop 1</b>  Review digital health projects identified from the mapping phase Identify what is working effectively and could be further developed more widely Recognise potential barriers to successful implementation  How do we categorise and cross link Cumbria Digital Health activity to enable development of a strategy framework?  Identifying the current projects which have the scope to be developed further in Cumbria	Needs analysis for digital health delivery in GP practices in Cumbria: preliminary findings from interviews with practices by Dr Jae-Llane Ditchburn, University of Cumbria  Key themes in rural health and social care worldwide and their relevance in Cumbria; preliminary findings from literature review by Keith Jackson, University of Cumbria  Mapping of digital health projects in Cumbria by Dr Jae-Llane Ditchburn, University of Cumbria





## Appendix I: cont'd

Date	Location	Events/discussions/group work	Rural health topics discussed
9 Dec 2014	County Hall, Kendal (28 attendees)	Digital Strategy Roadmapping Workshop 2  Discuss the proposed strategy roadmap Plan possible implementation projects  Implementation planning exercise: <ol style="list-style-type: none"> <li>1) Improve health outcomes for those with long term conditions, support more to self-manage</li> <li>2) Explain, clarify, share good (and bad) practice, assess impact and value</li> <li>3) Develop a digital-health-ready workforce</li> </ol>	NHS Personalised Health and Care 2020: Using data and technology to transform outcomes for patients and citizens. Overview and discussion – what does it mean for Cumbria? Presented by John Roebuck, Cumbria Clinical Commissioning Group  Draft of the Digital Roadmap – proposals from the study work by the University of Cumbria, presented by Alison Marshall, University of Cumbria  Update on rural transport by Lorraine Smyth, Action with Communities in Cumbria
11 Feb 2015	Cumbria Rural Enterprise Agency, Penrith (20 attendees)	Digital Strategy Roadmapping Workshop 2  Cumbria Rural Health Forum website  Implementation planning exercise: Meet the 'Rurals' – a typical Cumbrian family. How can we design digital services for them?	Healthwatch and Public Involvement Association update on discussions on rural health and patient transport by Cath Gleeson  Organisational readiness for digital health and the Telehealth Readiness Tool by Alison Marshall
15 Apr 2015	University of Cumbria, Fusehill Street campus, Carlisle (18 attendees)	Review of the Cumbria Rural Health Forum, development, current progress, benefits and what has worked well  Update on the Technology Enabled Care Round Table and Event by Peter Knock, Cumbria County Council  Comments and feedback on the forum by answering a member survey	Joint Strategic Needs Assessment for Cumbria 2015 by Emma Graham, Cumbria Public Health  Patient transport, consultation and developments by Lorraine Smyth, Action for Communities in Cumbria



## Appendix II: Digital health in general practice – general practitioner perceptions

### General practitioners' attitudes and experiences of digital health care

In order to better understand how digital technologies can enhance primary care from a general practitioner's perspective, 15 GPs were surveyed by face-to-face interview, email and phone. They were asked to reflect on their experiences of using technology, to consider which services technology would be most helpful in supporting and to highlight any issues and concerns.

Most GP consultations are face-to-face (surgery appointments, home visits), with a substantial proportion of GPs now using phone calls to supplement this. Some practices are starting to use social media for health education and general health questions. GPs were asked how they think technology could improve their practice.

### Suggested uses of digital technology to improve practice

- *Health education and prevention*
  - Tailored information sheets and advice
  - Some practices making use of Twitter and Facebook for general advice. It can help reduce demand for GP involvement in minor illnesses, through using social media for health education and more efficient provision of advice.
  - Medical reference apps for GPs
- *Secure messaging or email*
  - Email was generally perceived as being valuable (in principle) to support health management in patients.
  - Two GPs used email to communicate with a small number of known and trusted patients.
  - It has the potential to improve transactional efficiency in primary care through reaching the patient via technology – possibly through secure messaging or email, to let the patient know of test results.
- *Remote consultations via video-links*
  - No GPs currently undertook remote video consultations and there were mixed reactions to the idea of doing so.
  - Some GPs thought remote consultations should be trialled and offered as an option for patients – it could be a useful compromise between face-to-face (the best option) and a phone call (necessary for the convenience of the patient).
  - The main value may be in providing better access to secondary care.
  - GPs did not believe remote consultation would reduce workload but acknowledged that it might speed up referral times and offer cost-effective alternatives to patients having to travel distances to see their doctors.
- *Remote secure access to patient data*
  - Digital access to the patient database via mobile devices or laptops would save GPs time and mean they had the right clinical information when with the patient.
- *Improve the primary–secondary care interface*
  - Use video and better data sharing between GPs and consultants.
- *Telehealth*
  - Some GPs had experience of telemonitoring or telehealth systems (such as Florence Simple Telehealth System), which were felt to offer potential value.

### Issues and concerns

- The level of acceptance was mixed, with some seeing it as an essential enabler, others expressing more caution.
- One interviewee was of the view that primary care was already sufficient without technology.
- Health equity was raised as a concern, as it may be mainly higher socioeconomic groups that have access to smartphones, email and home broadband.
- The limitations of broadband and mobile phone coverage in Cumbria are a restriction.
- Funding to invest in equipment and infrastructure has been a constraint.
- Patient emails need to be integrated into the core clinical software system for GPs so that the email becomes part of the sessional work – although it may seem like email to the patient.
- However, respondents were concerned about:
  - data governance risks and security issues
  - being inundated with emails from patients
  - email being viewed as outside of the core clinical work package for doctors
  - the difficulty of clinically interpreting emails from patients without interacting with them
  - the possibility that email consultations would increase the likelihood of legal liability in the event of any incorrect diagnosis or 'missed' symptoms presented by the patient.

### Audit of GP workload

Four GPs reviewed a day's work. Results showed that 39% of patient cases could have been dealt with digitally. Examples are:

- cases where symptoms or health conditions can adequately be described over the telephone or by email
- follow-up appointments where patients have already been diagnosed and treated – for example checking health symptoms
- discussions regarding health conditions and test results
- requests for information
- reviewing prescriptions and health conditions
- consultations not requiring hands on (ie physical examination, medical procedures, bio measurements)



## Appendix II: cont'd

### *Some quotes from study participants*

*If you're worried about something, would a phone- or video-call be enough for you, or would you like to visit face to face and talk to someone and see the whites of their eyes? – see how they talk to you, it's also competence isn't it? If you don't know the individual, and you don't have that link of confidence, you probably want to see them face to face.*

*... if we could have iPads in our cars and we could afford them, we could speed up our consulting with patients in their homes because we would have at the end of our fingers all of their details without printing off the information on paper all the time.*

*... video consultations? Yes, absolutely, it would be achievable if we had decent broadband providing that we have security governance in place, but will also need a faster broadband – depends on case, but follow-ups, absolutely.*

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## Appendix III: Using technology to manage long term conditions – patient perceptions, attitudes and experiences

### Patients with long term conditions – attitudes and experiences of digital healthcare

Twenty-two people with long term conditions of fibromyalgia, myalgic encephalomyelitis and acquired brain injury were interviewed and asked to reflect on their experiences of receiving healthcare services and how they could see technology being used.

Participants were recruited through patient support groups and were in the age range 25–66 years (mean age 47) – 3 men, 19 women.

Many of the patients reported one or more secondary long term conditions in addition to the primary one: hypermobility syndrome (4), chronic pain (12), arthritis (4), diabetes (3), irritable bowel syndrome (3), periodic depression (2), osteoporosis (2), spinal stenosis (1), chronic cough (2), sleep apnoea (1), vitamin D deficiency (1), dystonia (1), pernicious anaemia (1), Barrett's oesophagus (1), bipolar disorder (1).

### Attitudes to technology

- Most were active on social media and used the internet for utility purposes, accessing information, networking and entertainment.
- Half of the participants reported using health apps and health monitoring devices, particularly medication reminders and pain diary apps.
- However, a few participants were unfamiliar with using any form of computer or mobile device.
- Of those that did use technology, some reported that they found it helpful for informally managing their condition, through friends and online patient communities.
- 'Helps me feel I'm not alone ... helps with benefit claims, enables me to help others in similar situations ...'
- 'Internet gives me the chance to participate in so many things, and contact people, which due to my condition I wouldn't be able to do without it.'

### Shared patient records

- Many patients reported difficulties in getting their condition satisfactorily diagnosed and frustrations at different professionals not having their full history to hand.
- Some patients also noted that they would like to have access to their records so they could ensure key information is noted.
- 'If I could access my own records pre my GP appointment, I could read my consultant's letter and attend my GP appointment more prepared.'
- 'I think it's about time, saves you trying to explain your condition/s over and over to each service provider.'
- 'I would love to be able to access my medical notes and care in one package, where there are contact links for everyone dealing with my specific case/needs and be able to access from PC and mobile devices.'
- 'This should already be in place. So many of our health records are not up to date, or the doctors don't read them.'

### Awareness of technology for self-management

- Patients were generally not aware of telehealth solutions for remote monitoring and had not been offered this as an option.
- Some patients indicated that they would like to monitor pain and other symptoms, but were unaware of apps or other products that could help with this.

### Digital communications with medical professionals

- Participants were asked to comment on preferences for face-to-face consultations and other means (telephone, email, video/Skype). Views were mixed.
- Several participants preferred face-to-face and felt that other forms of communication were a compromise.
- It was noted that face-to-face appointments are essential if a physical examination is required.
- Many participants, however, would welcome the convenience and saving a journey that could be uncomfortable, painful and tiring.
- Use of digital communications would also save considerable costs and time to patients, many of whom needed to use taxis or ask someone else to accompany them.
- There was some scepticism about remote appointments or the potential effectiveness of videoconferencing because participants felt that there would not be any flexibility on the side of their healthcare provider in accommodating appointments for them.

### Some quotes from study participants

*I have never used Skype, but if it meant getting appointments or consultations quicker then I would give it a try.*

*Often when I have struggled to an appointment I am in a lot of pain and suffering cognitive problems which mean I cannot concentrate or express myself properly. If I could email, I could put things in writing in my own pace.*

*I would be very pleased if I could email someone to clarify my understanding of what's happened in consultant appointments. Or just to get general answers about particular conditions.*

*I am unable to know until the day whether or not I can attend as on average I am only well enough to leave the house a couple of days a week.*

### Conclusions











Participant responses indicated a need for digital technologies amongst people with long term conditions in terms of:

- management of health condition
- maintenance of continuity of care
- enabling access to health care.

Addressing the issues faced by people with long term conditions by integrating digital technologies into a variety of clinical and social settings may improve their quality of life.



## Appendix IV: Outline of Twitter chats using the hashtag #CRHFchat (online on <https://storify.com/CumbriaRHFcrhfchat>)

Date	Theme and discussion	Sample tweets
23 March 2015	<p><i>#CRHFchat on digital health and social care</i></p> <p>Eleven users were online. As this was the first Twitter chat held by the forum, an open approach was taken to conduct the discussion. The following was discussed:</p> <ul style="list-style-type: none"> <li>uses of social media technologies in health and social care</li> <li>how to introduce people to technology</li> <li>how to support people who were either non-users or low users of technology</li> <li>how to bridge the gap between tech-users and slow-adopters or non-users.</li> </ul>	<p> <b>Tom Bell</b> @TominCumbria <a href="#">Follow</a></p> <p>Interesting to see Social Media attracted GPs to rural community at Millom...did we just shift resources not create new solutions? <a href="#">#crhfchat</a> 8:40 PM - 23 Mar 2015</p> <p> <b>My Way Code®</b> @MWCsoni <a href="#">Follow</a></p> <p><a href="#">@CumbriaRHF</a> <a href="#">#CRHFchat</a> Reduce isolation, update, connect and inform 8:15 PM - 23 Mar 2015</p>
20 April 2015	<p><i>Will digital technology free up resources or overburden an already stretched provision?</i></p> <p>Eight users discussed:</p> <ul style="list-style-type: none"> <li>benefits and uses of digital technology</li> <li>which was more influential in adopting digital technologies in primary care: patients or general practitioners</li> <li>reluctance of health professionals to use apps</li> <li>queries for training programs specially tailored for clinicians.</li> </ul>	<p> <b>Farhan Amin</b> @patientmemoirs <a href="#">Follow</a></p> <p><a href="#">@SeascaleHC</a> <a href="#">@CumbriaRHF</a> can use skype, facetime etc using emis pt access app on iphone/ipad <a href="#">#crhfchat</a> to transfer images+parameters :) 8:24 PM - 20 Apr 2015</p> <p> <b>Dr Umesh Prabhu</b> @DrUmeshPrabhu <a href="#">Follow</a></p> <p><a href="#">@CumbriaRHF</a> <a href="#">@SeascaleHC</a> family confident, got to learn technology, less travelling and so on. <a href="#">#CRHFchat</a>! 8:15 PM - 20 Apr 2015 · Manchester, England, United Kingdom</p> <p> <b>#hellomynameisGareth</b> @GarethPresch <a href="#">Follow</a></p> <p><a href="#">@CumbriaRHF</a> <a href="#">@DrUmeshPrabhu</a> <a href="#">@SeascaleHC</a> systems based on need - integration is key 📱 open source has benefits. <a href="#">#CRHFchat</a> 8:24 PM - 20 Apr 2015</p>
18 May 2015	<p><i>Digital health training for health professionals</i></p> <p>Thirteen users discussed:</p> <ul style="list-style-type: none"> <li>how to get clinicians to engage with digital technologies</li> <li>compulsory digital health training for new clinical graduates</li> <li>whether the health system may adequately support digital innovation</li> <li>examples of #telehealth.</li> </ul>	<p> <b>NHS Digital Health</b> @DigiHealth_ <a href="#">Follow</a></p> <p><a href="#">#CRHFchat</a> <a href="#">@CumbriaRHF</a> <a href="#">@UoC_CaChET</a> the tech develops quickly but system doesn't. Good case studies on innovation helps 8:22 PM - 18 May 2015</p> <p> <b>Marc Schmid</b> @MarcSchmid <a href="#">Follow</a></p> <p><a href="#">@CumbriaRHF</a> <a href="#">#CRHFchat</a> lack of understanding in the system is a major barrier to rolling out digital health 8:06 PM - 18 May 2015</p>
15 June 2015	<p><i>Talking apps – do apps have a role in health and social care? How? Why?</i></p> <p>Twelve users discussed:</p> <ul style="list-style-type: none"> <li>currently available health apps such as the National Health Service app</li> <li>useful links</li> <li>how colleagues (in health care) would like apps to work for them</li> <li>popular apps and how to encourage use.</li> </ul>	<p> SeascaleHC liked.</p> <p> <b>East Cumbria GPTP</b> @EastCumbriaGPTP · 15 Jun 2015 <a href="#">@CumbriaRHF</a> <a href="#">@ClaireMaddison3</a> <a href="#">#CRHFchat</a> Data on apps needs to be useful GP and patient. Work with GP clinical system. @newsfrommemis</p> <p> SeascaleHC liked.</p> <p> <b>Angela White</b> @health_excel · 15 Jun 2015 <a href="#">@CumbriaRHF</a> <a href="#">@SeascaleHC</a> <a href="#">@UoC_CaChET</a> @TominCumbria or we work with grps of patients/Clients with known problem to develop solution <a href="#">#CRHFchat</a></p>

